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## Personal information documents for people with dementia: healthcare staff's perceptions and experiences

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**Title: Personal information documents for people with dementia: healthcare staff's perceptions and experiences**

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## **Title: Personal information documents for people with dementia: healthcare staff's perceptions and experiences**

### **Abstract**

Person-centred care is internationally recognised as best practice for the care of people with dementia. Personal information documents for people with dementia are proposed as a way to support person-centred care in healthcare settings. However, there is little research about how they are used in practice. The aim of this study was to analyse healthcare staff's perceptions and experiences of using personal information documents, mainly Alzheimer's Society's 'This is me', for people with dementia in healthcare settings. The method comprised a secondary thematic analysis of data from a qualitative study, of how a dementia awareness initiative affected care for people with dementia in one healthcare organisation. The data were collected through 12 focus groups (n=58 participants) and 1 individual interview, conducted with a range of healthcare staff, both clinical and non-clinical. There are four themes presented: Understanding the rationale for personal information documents; Completing personal information documents; Location for personal information documents and transfer between settings; Impact of personal information documents in practice. The findings illuminated how healthcare staff use personal information documents in practice in ways that support person-centred care. Practical issues about the use of personal information documents were revealed and these may affect the optimal use of the documents in practice. The study indicated the need to complete personal information documents at an early stage following diagnosis of dementia, and the importance of embedding their use across care settings, to support communication and integrated care

**Keywords:** Dementia, person-centred care, personal information documents, communication, healthcare, care transitions

### **Introduction**

Globally, there are an estimated 47 million people living with dementia, a figure set to rise to 131 million by 2050 (Alzheimer's Disease International [ADI], 2016). In the United Kingdom (UK), there are an estimated 850,000 people, a figure expected to increase to over 1 million by 2025 (Prince et al., 2014). There is international agreement that person-centred care is

best practice for people with dementia but it is often not well delivered in hospitals (Dewing & Dijk, 2016). Personal information documents, which are also referred to as personal (or patient) profiles or passports, could support person-centred care by communicating important personal information that helps staff approach each person as a unique individual. These documents are increasingly being used in UK hospitals (Royal College of Psychiatrists [RCP], 2017) but there is a lack of evidence of how they are used in practice, what optimises their use or what impact they have on care for people with dementia in hospital. This paper helps to fill this gap by reporting on findings from a qualitative study about healthcare staff's perceptions and experiences of using personal information documents with people who have dementia.

## **Background**

Most people with dementia have complex comorbidities and they are more likely to be admitted to hospital than people without dementia, who are of a similar age and health condition; an estimated third of hospital inpatients in high income countries have dementia (Alzheimer's Disease International [ADI], 2016). The process of hospital care is more complicated for people with dementia (ADI, 2016) and the unfamiliar, busy and task focused hospital environment, along with the person's illness or injury, can increase both dementia symptoms and risk of delirium (RCP, 2017). The presence of dementia affects the person's treatment, care and recovery in hospital (Health Foundation, 2011) and people with dementia have lengthier hospital stays (ADI, 2016). Whilst more effective care at home could reduce hospital admissions, the growing older population and new treatments available mean that older people with dementia will continue to be core service users in hospitals (RCP, 2013). Therefore, hospitals must be able to effectively meet the needs of people with dementia (Oliver, Foot & Humphries, 2014) and provide the high quality care needed (ADI, 2016). However, care pathways for people with dementia, the care environment, ethos and resources in hospital all need improving (Houghton, Murphy, Brooker & Casey, 2016).

Healthcare for people with dementia should be holistic and consider the person's unique context, values and preferences (ADI, 2016). Person-centred approaches for people with dementia, based on seminal work on the uniqueness of each person with dementia (Kitwood, 1997), are considered synonymous with best quality care (Dewing & Dijk, 2016; Edvardsson, Fetherstonhaugh & Nay, 2010; Oliver et al., 2014). Building from Kitwood's work, Brooker (2004) presented the VIPS framework for person-centred care, comprising: valuing people with dementia and carers (V), treating people as individuals (I), using the perspective of the person with dementia (P) and a positive social environment (S). However, hospital care has been found to be task-orientated with a lack of focus on the individual (Clissett, Porock, Harwood & Gladman, 2013; Dewing & Dijk, 2016). Consequently, people may experience negative effects on their dementia from hospitalisation, mainly arising from tensions between the prioritisation of acute care for concurrent co-morbidities, and the provision of person-centred dementia care (Dewing & Dijk, 2016). Improved care for people with dementia in general hospitals has become a 'policy and practice imperative'; staff need to recognise the benefits of person-centred care and have the ability to deliver person-centred care in practice (Turner, Eccles, Elvish, Simpson, Keady, 2017).

Getting to know the person with dementia is a central feature of person-centred care and is fundamental to the process of life story work, which thus has potential to enhance person-centred care for people with dementia (McKeown, Clarke, Ingleton, Ryan & Repper, 2010). Life story work ranges in breadth, depth and structure (Eley & Kaisar 2017) but has been described as working with a person and/or their family, to find out about their life, recording the information and using it in practice with the person (McKeown et al., 2006). Approaches to life story work often use a story book and much of the life story research has been conducted in long-term settings or services, notably residential care (Berendonk & Kaine, 2016; Edvardsson et al., 2010; Kellett et al., 2010; Moos & Bjorn, 2006; Russell & Timmons, 2009) or mental health care (McKeown, Ryan, Ingleton & Clarke, 2015). Personal information documents (or personal profiles) for people with dementia have drawn on the

principles underlying life story work, that of getting to know the person who has dementia, by recording key information in a brief and accessible document for staff to use. Used effectively they could assist the recording and sharing of personal information (Chater & Hughes, 2012). They are not strictly life story work but may help to increase understanding of the person and improve individualised care in a simple and practical way (Thompson, 2017).

The UK's Alzheimer's Society 'This is me' leaflet, which was first published in 2010, is an example of a tool for recording personal information about an individual with dementia. Alzheimer's Society (2017) proposes that 'This is me' can be used in any setting to help facilitate person-centred care. The document enables the recording of key information about the person: preferred name, background (family, friends), current and past interests, jobs and places lived and visited, routines important to the person, things that may worry or upset the person, what makes the person feel better if they are anxious or upset, hearing and eyesight, communication method, mobility, sleep, personal care, how the person takes their medication, eating and drinking, other information. Following an audit of dementia care in hospitals in England and Wales, the RCP (2011) recommended that a personal information document, like 'This is me', should be implemented. The RCP's (2013) second audit of dementia care found that the collection of personal information was an area that still needed improving. In the most recent audit (RCP, 2017), 99% of hospitals reported that they had a system for personal information documents for people with dementia but in practice, only half the patients audited had such a document and there were gaps in the information collected. Only 60% of staff surveyed had access to the personal information they needed to care for individuals with dementia (RCP, 2017). Therefore, there appeared to be a gap between organisational awareness and commitment to personal information documents for people with dementia, and their application in practice, thus reducing potential impact. Sampson et al. (2017) reported that following a dementia training programme, use of 'This is me' substantially increased but it was not known how frequently they were actually used in

practice. As well as 'This is me', there are other examples of personal information documents, for example, 'Getting to know me' (Elvish et al., 2014). However, there has been little evaluation of use and implementation of personal information documents (Thompson 2017).

In summary, person-centred care is considered best practice for people with dementia but has been found difficult to provide in hospital. Personal information documents could help hospital staff to access important information that increases understanding of an individual's preferences and needs. There is a lack of research about how personal information documents are used for people with dementia in hospital and their impact in practice. This paper reports on a secondary analysis of data from a qualitative study of how a dementia awareness initiative affected care for people with dementia in one healthcare organisation. The aim of this secondary analysis was to analyse healthcare staff's perceptions and experiences of using personal information documents for people with dementia. The research questions addressed were:

- 1) What are healthcare staff's perceptions and experiences of using personal information documents for people with dementia?
- 2) How do healthcare staff use personal information documents for people with dementia in practice?

## **Method**

### ***The healthcare setting***

The setting was a National Health Service (NHS) system ('Trust') in London, England, that included two large hospitals and community services. Similar to other large city NHS Trusts, it provided a full range of health services, including emergency care, to the local population, as well as specialist services to a wider population across London and the south of England. In 2012, the Trust launched a project to improve staff dementia awareness, using a series of

films 'Barbara's Story' (see <http://burdetttraininghub.org.uk/?platform=hootsuite>) in two phases, which showed the experience of healthcare from the perspective of an older woman ('Barbara') who has dementia. The films illustrate that whether she is treated as a valued person and as an individual affects her care experience, thus highlighting principles of person-centred care (Brooker, 2004). At the same time as the dementia awareness project, the Trust was implementing initiatives to improve care of people with dementia. One such initiative was a personal information document, Alzheimer's Society's 'This is me', which was featured in one of the later films, where a nursing assistant is shown completing 'This is me' with Barbara.

### ***Study design***

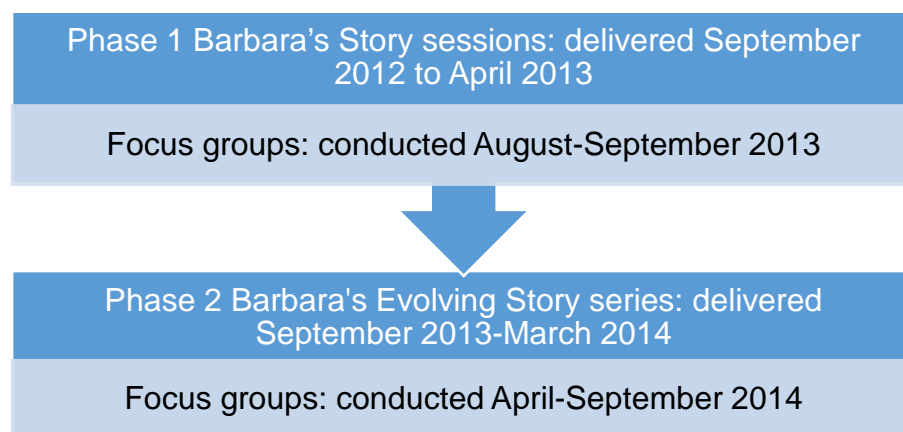
The overall study's aim was to investigate staff perspectives of the effect of Barbara's Story on themselves, their colleagues and the organisation; the full study design and findings have been previously published (Baillie et al., 2016). The study was qualitative and took a social constructionist approach, with the view that people together create social phenomena (Berger & Luckman, 1996). A longitudinal design was used, comprising focus groups at two points, linked to the project's two phases (see Figure 1). Focus groups are ideal for exploring people's experiences, opinions, wishes and concerns (Kitzinger & Barbour, 1999) and they link individual and group interactions so subjective views are seen within a fuller social context (Burr, 1995). The interactions between the participants stimulate more ideas for discussion; these data created through interactions can provide insights into public discourse (Kitzinger, 1994).

The first Barbara's Story film was delivered in regular sessions with facilitated discussions from September 2012 to April 2013. The Phase 1 data collection took place in August-September 2013, approximately one year after the initial launch but before the second series of films 'Barbara's Evolving Story' started. One new episode, with multiple viewings, was then shown each month, completing in March 2014. The Phase 2 data collection took place from April-September 2014. In the Phase 2 focus groups, there were detailed discussions



about the use of personal information documents, in particular, 'This is me'. This paper reports on a secondary thematic analysis of the Phase 2 data about use of personal information documents to support care of people with dementia.

**Figure 1 Barbara's story project and the Phase 1 and Phase 2 focus groups**



### ***Participants and data collection***

Purposive sampling was used to include participants from different professions (clinical and non-clinical) and settings (both hospitals and community) and the aim was for group sizes of 6-10 people. In practice, due to the acute nature of the Trust, the facilitators had to be flexible and in Phase 2, group sizes ranged from 2-13 participants (see Table 1). In groups with only two staff, there was still rich discussion between them. Three individual interviews were conducted with nursing staff who could not leave their wards to attend a focus group, on one busy hospital site. The use of some interviews within an overall focus group design has been previously recognised as a pragmatic decision (Barbour, 2007).

As Table 1 shows, in 12 of the 16 focus groups (n=58 participants) and one of the three individual interviews, there was explicit reference to personal information documents, usually 'This is me', which was the document that was implemented in the Trust. Some participants had seen other similar documents, either in other settings where they had worked or

occasionally when brought into hospital with a patient. In some focus groups, there was only brief reference to the documents but in others there were lengthy discussions.

<b>Table 1 Phase 2 Focus groups and interviews</b>		
<b>Focus groups</b>		
<b>Identifier</b>	<b>Discipline</b>	<b>Number of attendees</b>
Nurses 1*	Nursing staff	3
Nurses 2	Nursing staff	3
Nurses3*	Nursing staff	2
Nurses4*	Nursing staff	5
Nurses 5	Nursing staff (outpatients)	10
Nurses 6*	Nursing staff (emergency department)	13
Nurses7*	Nursing staff	8
Nurses8*	Nursing staff	2
Nurses9	Nursing staff	2
Nurses12*	Nursing staff	2
Community*	Allied health professionals and district nurse	6
Therapists1	Allied health professionals	2
Therapists2*	Allied health professionals	5
Medical	Doctors	2
Non clinical1*	Non-clinical staff	7
Non clinical2*	Non-clinical staff	5
<b>Individual interviews</b>		
Nurse10	Registered nurse	1
Nurse11	Registered nurse	1
Nurse13*	Registered nurse	1
<b>All participants</b>		<b>80</b>
*Made explicit reference to personal information documents e.g. 'This is me' and included in secondary analysis		

Nursing staff included registered nurses of varied seniority and non-registered nursing assistants. Non-clinical staff included porters, housekeeping/catering staff, receptionists and training staff. Each focus group or interview was assigned a unique identifier, which are used to attribute data extracts in the results. The focus group topic guides were developed from the project aims, in discussion with the Trust project team. Open questions with follow-up probes were used to explore: recall and views about Barbara's Story; personal experiences and observations of care delivery since Barbara's Story launch, any changes within the organisation; sustainability; and further developments. The data about personal information documents arose mainly from questions about personal experiences and observations of

care delivery, and changes in the organisation. Focus groups were conducted in seminar rooms in varied sites across the Trust and interviews in ward offices. Each focus group was audio-recorded, lasted 35-60 minutes and was facilitated by two research team members, with one taking notes about non-verbal communication (for example, nodding). The individual interviews lasted 15-30 minutes and were conducted using the topics in the focus group guide.

### ***Data analysis***

The focus group/interview audio recordings were transcribed. For the secondary analysis reported in this paper, a thematic analysis was conducted manually, using the principles described by Braun and Clark (2006). All the Phase 2 transcripts were read through for familiarisation by one research team member. Then, data that were relevant to the use of 'This is me' or other personal information documents were extracted into a separate file. These data were then coded, all codes were reviewed and clustered, and then reviewed again for overarching themes.

### ***Ethical considerations***

Ethical approval was obtained from a university Research Ethics Committee. The study was registered with the Trust's Clinical Governance Department. The participants were invited to take part on a voluntary basis and all signed written consent forms prior to data collection starting. Invitation letters and information sheets were distributed. Participants were reminded that the discussion should remain confidential to the group. They were assured that they would only be identified by professional group and no individual would be identifiable.

## Findings

Four themes are presented: Understanding the rationale for personal information documents; Completing personal information documents; Location for personal information documents and transfer between settings; Impact of personal information documents in practice

### *Understanding the rationale for personal information documents*

Participants expressed that personal information documents for people with dementia, such as 'This is me', could help them to focus on the person, rather than the medical condition:

I think as soon as you find out someone has got dementia you relate everything back to the disease and that's what they don't want, to be defined by dementia, that's the whole point of 'This is me', remember who I am, not the illness that I have (Nurses8)  
Nurses discussed that 'This is me' provided 'a back story for the person' (Nurses4) and that 'This is me' could help staff to understand something of the person's life, for example, their previous profession.

Staff in several focus groups discussed that the information recorded could act as a communication tool, providing information that they could use when a person is upset:

When you see a patient with dementia who is distressed, it could be a simple fact that they want something but they can't effectively communicate it to you. But if you've got some sort of [information about them], it can help (Nurses4)

A group of emergency department nurses (Nurses6) discussed how 'This is me' provided different information from that found in medical notes and was essential for caring for a person with dementia, especially as they were often not accompanied by someone who knew them:

- If they come from a nursing home, fair enough it might be that much of an emergency, they don't have time to photocopy the notes, but if it's iterated that if all you have is a 'This is me', we would know at least who, what, where and when.
- How they like to be addressed
- Because a medical issue you can get from the medical notes and you can piece something together, but there are some things that you won't ever find out because they won't tell you. (Nurses6)

The nurses described that without this type of personal information: 'we are absolutely stumped' (Nurses6). In another focus group, however, one staff member expressed that people were overloaded with initiatives and targets to achieve and so, for 'This is me' to be fully embedded, staff really needed to appreciate what it could contribute to patient safety and care (Therapists2).

### *Completing personal information documents*

Participants considered it important to establish the best process for completing the documents: who completes the document, at what stage and in what setting? Without this common understanding, they were concerned that documents might not be fully completed or indeed at all. Discussions mainly revolved around the role of families and healthcare staff, involving the person with dementia at an early stage, and the feasibility of completing the documents in care homes, community or hospital settings.

Most staff considered that families were best placed to complete the documents and the involvement of the person with dementia was little mentioned. In one focus group there was the following exchange

- So the patient obviously can't fill it out.
- It's the relatives (Nurses8)

Such views were probably because of experiences with patients who had advanced dementia. However, in another focus group, staff discussed that:

It should be the family, friends, the people who know the individual. The individual if they still have the ability. (Nurses4)

They further discussed how important it was that 'This is me' was completed at an early stage:

- We had a lady, she's got dementia, obviously it's in beginning stage, and I said why has she not got a 'This Is me' document? It was like: 'she doesn't really need it'. I said but what if later on she gets readmitted, her dementia is worse, you've got some reference point.
- They can be updated as well on new admissions.
- The moment a person is diagnosed they should have it.
- I just think people don't realise that these things are the psycho-social aspect and people go, 'we haven't got time to do it' but actually if you take those few seconds to fill it in, in the long term it will save time (Nurses4)

Staff discussed positive experiences of 'This is me' being completed by families, for example:

There was one that was obviously written out by family and was nice and detailed and had lots of stuff in it. (Nurses6)

In other focus groups, nurses described giving the document to families to complete, or showing them how to access it on the internet from Alzheimer's Society, which families appreciated (Nurses1; Nurses4). In some focus groups, staff discussed that completing the document was problematic when there was no family (Nurses7; Therapists2). However, therapists discussed that they could involve other people in completing the documents, for example, a neighbour might know what TV programmes the person likes and what calms them down (Therapists2).

Whilst many staff considered that families were ideally placed to complete 'This is me', there were examples of hospital staff completing the document effectively, when families were unavailable. One example was of a patient from a care home whose wife was only rarely able to visit. The patient was on the ward for two weeks and the staff completed 'This is me' as a team over time:

Every nurse always found the time to have a little chat with him, then maybe go back a little bit, 'What did you do when you were young', and 'what's your favourite things?', and eventually over days and days they do start telling you all these important things, which then went into 'This is me', which became a great tool, and all of the important things to him were in there, all the things he liked and disliked, things that made him comfortable, made him upset, depressed, everything was in there by the end of two weeks. So a lot of the staff can do that as well, every little thing you learn about that particular patient you can just add it in and you'll be surprised how, at the end of a time, if they're there for a while especially, you'll have lots of information in there because everybody will learn something about that person. (Nurses7)

'Barbara's story' showed a nursing assistant completing 'This is me' with Barbara, when caring for her on a one-to-one basis as a 'special'. The therapists discussed that this could be a valuable part of the special's role:

The specials, if they were trained, part of your job is to put together a 'This is me' document, so really get to know your patient, enjoy being with them, what are they like, and really valuing that person. (Therapists2)

Emergency department nurses considered that care homes should have completed personal information documents for residents but they also discussed whether district nurses should complete the documents for people with dementia in the community and nursing homes, as part of their assessment, and upload them electronically; however, some staff considered this would have workload implications for district nurses (Nurses6). Some ward staff had good experience of the documents being completed for care home residents and accompanying the resident to hospital:

Most of our patients will come from nursing homes and so we do usually get a document from the nursing homes to say that the patient likes this, that and the other. (Nurses8)

Community staff had not seen 'This is me' in practice and their initial discussion implied expectations that it would be completed in hospital, and then transferred with the patient to the community, which would be useful for continuing care of the person. However, as their discussion continued, one participant noted:

I guess there is no reason why we couldn't actually complete it for them, if we find that we haven't got one in place already.

They later discussed that it could be easier to complete the document in the community rather than in hospital, as the person was in their own environment and family may be present.

#### *Location for personal information documents and transfer between settings*

Practical issues, such as where to keep completed personal information documents, so that they are accessible and easily found, and how to transfer the document between settings with patients, were discussed at length in some groups. One group suggested that 'This is me' could be scanned into the electronic patient record (EPR) (Therapists2). They further discussed whether it could be completed and uploaded to the EPR while the patient is in the community, as a paper version could be difficult to find and: '*if somebody is acutely unwell you're not going to faff around for a bit of paper*'. However, they also recognised that staff

across different settings may not be able to access the EPR as systems used can vary (Therapists2). Within the hospital, the therapists suggested that a completed 'This is me' should accompany patients to investigations in other hospital departments, such as radiography, so that staff there had access to key personal information too (Therapists2).

Emergency department nurses identified that it would be valuable if all care home residents were accompanied by a completed 'This is me': *'so the moment they come here at least we know the basics'* (Nurses6). Staff also identified the importance of a completed 'This is me' not being filed away in case notes where it could not be accessed (Nurses4; Nurses6). Similarly, therapists suggested that it should be *'on the front of the notes or somewhere visible that doesn't get pulled out of the notes'* (Therapists2). In one focus group, ward nurses discussed sending a completed 'This is Me' with a patient when he was transferred to a care home from the ward (Nurses7). A group of therapists identified the need for a sound process for transferring the completed documents across settings (e.g. hospital to care home/community and vice versa). They further questioned whose responsibility it was to ensure the document accompanied the patient and was handed over:

It's all very well us filling them out when they're here [in hospital], and then when they go home, how do we ensure that that then comes with them, because a lot of patients don't have that family network, it could get lost or is it the paramedic's responsibility for making sure they have it when they bring them here? (Therapists2)

They also discussed how to ensure that the document then accompanied the patient when they visited the hospital again, as otherwise multiple 'This is me' documents would be completed which *'loses its sense of appeal'* (Therapists2). Some discussions indicated that the issue about how the documents are transferred between settings with the individual linked to a wider issue about working in a more integrated way and, as a specific example, how relevant information about care home residents could be shared and accompany patients who attend hospital in an emergency (Nurses6).



### *Impact of personal information documents in practice*

In some focus groups, there were specific examples of the difference that personal information documents could make to caring for people with dementia, through staff having immediate access to information that they could use in their care of individuals. The examples ranged from knowing preferences that enhanced an individual's experience in hospital, to information that was really important for staff to deliver care, for example, how to approach a person who is distressed. In some instances, seemingly small details could have a significant impact on the delivery of person-centred care and indeed their safety too.

Participants really appreciated the importance of knowing the person and their preferences, for example, little things like how a person takes their tea:

It's nice to know a bit more about them, what they like and don't like, even if it's just down to how they like their tea or they don't like tea. (Nurses6)

In another focus group, nurses discussed that: *'it's sometimes the simplest things, like putting on the radio'* as some individuals would like to listen to radio while others would not (Nurses7). The nurses also considered that 'This is me' helped them to know the individual as a person, which assisted the building of a relationship and provided information that they could include in their interactions (Nurses7, Nurses12). In another focus group there were several examples of how using 'This is me' had positively impacted on practice:

It just made the care you gave so personalised and I remember the patient and it said in the notes, loves Coronation Street and EastEnders. So at 7.30pm I'd go and put on Coronation Street, just because I knew about it. (Nurses4)

As an example of the importance of knowing personal information that triggered distress, and the best way to manage the situation, a nurse described experiences with a woman with dementia whose daughter had died 20 years ago:

There is a little box on the bottom of 'This Is me' that says, 'things that may worry or upset me'. So the husband filled it in, she was an elective patient for surgery, vascular dementia, and she'd come in for an elective procedure and she'd got this 'This Is me', that information was there to say 'when I get anxious I call for my daughter and she died 20 years ago'. (Nurses4)

The woman did become distressed and started calling for her daughter but her husband provided information for the staff of how to manage the situation, informing them:

'I talk to her about all the wonderful memories we've got of our daughter, all that sort of thing' and then, he said, 'I use a distraction technique, go to the window, put the telly on, whatever it might be, and we'll talk about something'. So he spent quite a time and put a big A4 sheet of bullet points of memories of the daughter for the staff to interact with. That worked really well. (Nurses4)

In the nurse's view, being able to relieve the woman's distress, through the information the husband provided, alleviated any possibility of sedation, which would have affected the patient's eating and drinking and impacted on recovery. The patient recovered well from her surgery and was discharged as planned.

## **Discussion**

There is increasing recognition of the importance of understanding individuals' experiences and perspectives within healthcare (Baillie et al. 2017), and indeed patient stories can be considered an alternative form of knowledge (Rose and Gidman 2010). Initiatives such as digital storytelling (Hardy and Sumner, 2015) provide readily available first person insights for healthcare professionals to appreciate people's individual experiences, including those of people who are living with dementia (see: <https://www.patientvoices.org.uk/>). Understanding each individual's perspective is one of the principles of person-centred care for people with dementia (Brooker, 2004). Similarly to the principles underpinning digital stories, personal information documents for people with dementia, such as 'This is me', provide a way for healthcare professionals to understand the individual's perspective on what is important for them and their care, which is particularly valuable where there are communication difficulties. However, the use of personal information documents in practice has been little investigated and so the secondary analysis conducted for this study has contributed by illuminating how the documents are used and how they can positively impact on person-centred care for people with dementia in hospital. These findings are therefore important, as previous studies have revealed barriers to providing person-centred care in hospital (Dewing & Dijk, 2016).

A caregiver who gets to know a person with dementia, is better placed to initiate conversations and meaningful activities (Edvardsson et al., 2010) and to provide care that is meaningful to the individual (Nolan, 2006). In this study, the staff discussions revealed an appreciation of the importance of understanding the person as an individual and not focusing on the dementia and medical condition alone. There were examples of how the personal information documents helped staff to know personal preferences for beverages and radio and television programmes. Staff also described how understanding people's backgrounds and what causes distress, influenced care delivery for people with dementia who could not verbally provide this information. However, healthcare workers should also be aware that personal information documents do only provide a glimpse of the person's biography and individual needs (Thompson (2017).

The study findings highlighted important practical issues such as who completes the documents and at what stage, where the documents are kept, and the processes necessary to ensure they accompany patients both within the hospital but also during care transitions. Some participants identified that completing the document at an early stage, so the person with dementia could be involved as well as families, would be ideal, and would require a proactive approach to completing the documents, perhaps soon after diagnosis. Equally important is to ensure that both the person with dementia and their families appreciate the importance of the document and keep it safely so it can accompany the person, if admitted to hospital or attending health appointments.

From a care home perspective, 69% of residents have dementia (Prince et al., 2014) and up to 75% of care home residents experience an unplanned transfer to hospital emergency departments (Dwyer, Gabbe, Stoelwinder, & Lowthian, 2014). Effective communication is essential for successful transitions between care homes and emergency departments (Dwyer et al. 2014; Griffiths, Morphet, Innes, Crawford, & Williams, 2014). A lack of

information, particularly about what causes agitation and strategies to use, was found to be problematic for emergency department staff in a study from the United States (Moore & Sullivan, 2017). Similarly, in the current UK study, emergency department nurses emphasised how important personal information was for their care of people with dementia but they were regularly caring for patients from care homes, with little or no personal information. The staff raised the importance of more integrated approaches to care for people with dementia, concurring with other calls for better integrated care for older people with complex needs, who frequently experience transitions between services (Aaltonen, Rissanen, Forma, Raitanen & Jylhä, 2012; Ellins et al. 2012). Some ward-based nurses had much better experiences of personal information documents accompanying people admitted from care homes. Also of note, is the importance of personal information documents accompanying people with dementia during moves within the hospital environment. Whilst moves should be kept to a minimum, currently people with dementia may experience multiple moves within the hospital setting and encounter numerous different staff (Thompson, 2017).

From an organisational perspective, the awareness and implementation of personal information documents in hospitals in England and Wales seems to have been achieved successfully with nearly all hospitals reporting that they have implemented the documents (RCP, 2017). However, the RCP (2017) revealed a gap between policy and practice, with only 49% of people with dementia having a personal information document present at their bedside or in their notes, and variable levels of completeness. For example, only 33% recorded factors that may cause distress, 29% recorded actions to calm the person if agitated, and 44% recorded food and drink preferences (RCP 2017). In the current study, there were rich examples of how valuable such information is in the care of people with dementia in hospital. The missing details in the RCP (2017) audit could result from difficulties in accessing information from the patient or from their families during an acute

hospital admission. This highlights that ideally the document would be completed in a more planned way and accompany the person between care settings.

The study was conducted in only one Trust in one geographical area of England, which is a limitation, and the study included staff perspectives only, following a dementia awareness initiative. The current study's setting had implemented one particular personal information document ('This is me') though some participants had seen other variations too. Some focus groups were much smaller than intended, due to difficulties in staff attending, but they still resulted in rich data, and a wide range of staff across the Trust participated. We recommend that further research should specifically focus on use of personal information documents and should include people with dementia and carers to gain their perspectives on these documents and how they affect care. There are a variety of personal information documents in use currently; and future research could focus on evidence about what type of document works best. Studies could include observation of how the documents are completed and used in practice, further examine impacts on person-centred care, and investigate what processes work best for the use of these documents, particularly during care transitions.

In conclusion, there is a need for effective interventions that can support the delivery of person-centred care for people with dementia in hospital. One important element that supports person-centred care is for healthcare staff to access key information about individuals so that they can ensure inclusion of their perspectives and preferences during care delivery. Personal information documents aim to communicate important information about individuals who have dementia and so they have been recommended as a way of supporting person-centred care for people with dementia. However, there has been a lack of previous research about how they are used in practice. The paper has presented research findings that illuminate how healthcare staff use personal information documents in practice in ways that support person-centred care, through an enhanced understanding of the person's preferences and background. Practical issues about the use of personal information documents have also been revealed and these may affect the optimal use of the

documents in practice. The study also has wider implications across sectors as personal information documents may be best completed by an individual at an early stage following their diagnosis of dementia and, to support communication and integrated care, their use needs embedding across care settings.

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## **Declaration of interests**

The Authors declare that there is no conflict of interest

## **References**

- Aaltonen M, Rissanen P, Forma L, Raitanen J, & Jylhä M. (2012). The impact of dementia on care transitions during the last two years of life. *Age and Ageing*, 41:52–7.
- Alzheimer's Disease International (2016). *World Alzheimer Report 2016: Improving healthcare for people living with dementia coverage, Quality and costs now and in the future*. London: Alzheimer's Disease International. Retrieved from: <https://www.alz.co.uk/research/WorldAlzheimerReport2016.pdf>
- Alzheimer's Society (2017). *This is me: This leaflet will help you support me in an unfamiliar place*. Retrieved from: [https://www.alzheimers.org.uk/download/downloads/id/3423/this\\_is\\_me.pdf](https://www.alzheimers.org.uk/download/downloads/id/3423/this_is_me.pdf)
- Barbour, R.S. (2007), *Doing Focus Groups*, Los Angeles, Sage Publications.
- Baillie, L., Maxwell, E., Thomas, N. (2016) The service user and carer perspective. In: McSherry, W. (Ed) *Stories of Dignity within Healthcare: Research, narratives and theories*. Cumbria: M&K Publishing, pp97-110.
- Baillie, L., Sills, E., Thomas, N. (2016) Educating a health service workforce about dementia: a qualitative study. *Quality in Ageing and Older Adults*. 17(2): 119-130.
- Berger, P., & Luckmann, T. (1966). *The Social Construction of Reality*, London, UK: Penguin Press.
- Berendonk, C. & Caine, V. (2016) Life story work with persons with dementia in nursing homes: A Grounded Theory study of the perspectives of care staff. *Dementia* 0(0) 1–21
- Braun, V. & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3 (2). 77-101.
- Brooker, D. (2004). What is person-centred care in dementia? *Reviews in Clinical Gerontology*, 13(3), 215-222.
- Burr, V. (1995). *An Introduction to Social Constructionism*, London, UK: Routledge.
- Chater, K., & Hughes, N. (2012). Strategies to deliver dementia training and education in the acute hospital setting. *Journal of Research in Nursing*, 18(6): 578-593.

Clissett, P., Porock, D., Harwood, R. H. & Gladman, J. R. F. (2013). The challenges of achieving person-centred care in acute hospitals: A qualitative study of people with dementia and their families. *International Journal of Nursing Studies*, 50, 1495–1503.

Dewing, J. & Dijk, S. (2016). What is the current state of care for older people with dementia in general hospitals? A literature review. *Dementia*, 15(1), 106-24.

Dwyer, R., Gabbe, B., Stoelwinder, J. U. & Lowthian, J. (2014), A systematic review of outcomes following emergency transfer to hospital for residents of aged care facilities. *Age and Ageing*, 43 (6), 759-766.

Edvardsson, D., Fetherstonhaugh, D. & Nay, R. (2010). Promoting a continuation of self and normality: person-centred care as described by people with dementia, their family members and aged care staff. *Journal of Clinical Nursing*, 19, 2611–2618.

Eley, R. and Kaiser, P (2017) Introduction in: Kaiser P. & Eley R. (eds) (2017) *Life Story work with people with dementia – Ordinary Lives, Extraordinary People*. London: Jessica Kingsley Publishers.

Ellins, J., Glasby, J., Tanner, D., McIver, S., Davidson, D., Littlechild, R., Snelling, I., et al. (2012). Understanding and improving transitions of older people: a user and carer centred approach. Final report. NIHR Service Delivery and Organisation programme. Retrieved from: <http://www.birmingham.ac.uk/Documents/news/SDOTransitions-Report.pdf>.

Elvish, R., Burrow, S., Cawley, R., Harney, K., Graham, P., Pilling, M., Gregory, J., Roach, P., Fossey, J., Keady, J. (2014). ‘Getting to Know Me’: the development and evaluation of a training programme for enhancing skills in the care of people with dementia in general hospital settings. *Aging & Mental Health*, 18, 4, 481–488.

Griffiths, D., Morphet, J., Innes, K., Crawford, K. and Williams, A. (2014). Communication between residential aged care facilities and the emergency department: A review of the literature. *International Journal of Nursing Studies*, 51(11), 1517-1523.

Hardy, P., Sumner, T. (2015) *Cultivating Compassion: How digital storytelling is transforming healthcare*. Chichester: Kingsham Press.

Health Foundation (2011). *Spotlight on dementia care. A Health Foundation Improvement report*, London, UK: The Health Foundation.

Houghton, C., Murphy, K., Brooker, D., Casey, D. (2016), Healthcare staffs’ experiences and perceptions of caring for people with dementia in the acute setting: Qualitative evidence synthesis. *International Journal of Nursing Studies*, 61, 104–116.

Kellett, U., Moyle, W., McAllister, M., King, C., Gallagher, F. (2010). Life stories and biography: a means of connecting family and staff to people with dementia. *Journal of Clinical Nursing*, 19(11-12): 1707-1715.

Kitwood, T. (1997). *Dementia reconsidered: the person comes first*. Buckingham, UK: Open University Press.

Kitzinger, J. (1994). The methodology of focus group interviews: the importance of interaction between research participants. *Sociology of Health and Illness*, 16, 103–121.

- Kitzinger, J., & Barbour, R.S. (1999). Introduction: the challenge and promise of focus groups. In Barbour, R.S. & Kitzinger, J. (Eds) *Developing Focus Group Research: Politics, theory and practice* (pp1-20). London, UK: Sage Publications.
- McKeown, J., Clarke, A. & Repper, J. (2006) Life story work in health and social care: systematic literature review. *Journal of Advanced Nursing* 55, 237–247.
- McKeown, J., Clarke, A., Ingleton, C., Ryan, T., Repper, J. (2010). The use of life story work with people with dementia to enhance person-centred care. *International Journal of Older People Nursing*, 5, 148–158.
- McKeown, J., Ryan, T., Ingleton, C., Clarke, A. (2015). 'You have to be mindful of whose story it is': The challenges of undertaking life story work with people with dementia and their family carers. *Dementia*, 14(2), 238–256.
- Moore, J., Sullivan, M. (2017). Enhancing the ADMIT Me Tool for Care Transitions for Individuals With Alzheimer's Disease. *Journal of Gerontological Nursing*, 43(5), 32-38.
- Moos, I. Bjorn, A. (2006) Use of the life story in the institutional care of people with dementia: a review of intervention studies. *Ageing & Society*, 26, 431–454.
- Nolan, L. (2006). Caring connections with older persons with dementia in an acute hospital setting – a hermeneutic interpretation of the staff nurse's experience. *International Journal of Older People Nursing*, 1, 208-215.
- Oliver, O., Foot, C., & Humphries, R. (2014). *Making our health and care systems fit for an aging population*. London: King's Fund.
- Prince, M., Knapp, M., Guerchet, M., McCrone, P., Prina, M., Comas-Herrera, A., Wittenberg, R., & Salimkumar, D. (2014). Dementia UK: Update. London: Alzheimer's Society. [Online] Retrieved from: [https://www.alzheimers.org.uk/download/downloads/id/2323/dementia\\_uk\\_update.pdf](https://www.alzheimers.org.uk/download/downloads/id/2323/dementia_uk_update.pdf)
- Rose, P., Gidman, J. (2010). Patient experience as evidence. In: Rose, P., McCarthy, J. (Eds.), *Values Based Health and Social Care: beyond Evidence Based Practice*. Sage, London
- Royal College of Psychiatrists (2011). Report of the National Audit of Dementia Care in General Hospitals. Editors: Young, J., Hood, C., Woolley, R., Gandesha, A., Souza, R. London, UK: Healthcare Quality Improvement Partnership.
- Royal College of Psychiatrists (2013). National Audit of Dementia care in general hospitals 2012-13: Second round audit report and update. Editors: Young J, Hood C, Gandesha A and Souza R. London, UK: HQIP.
- Royal College of Psychiatrists (2017). National Audit of Dementia Care in General Hospitals 2016–2017 Third Round of Audit Report. London: Royal College of Psychiatrists. Retrieved from: [http://www.rcpsych.ac.uk/pdf/National\\_Audit\\_of\\_Dementia\\_online\\_version\\_FINAL.pdf](http://www.rcpsych.ac.uk/pdf/National_Audit_of_Dementia_online_version_FINAL.pdf)
- Russell, C., Timmons, S. (2009). Life story work and nursing home residents with dementia. *Nursing Older People*, 21(4), 28-32.



Sampson, E.L., Vickerstaff, V., Lietz, S., Orrell, M. (2017). Improving the care of people with dementia in general hospitals: evaluation of a whole-system train-the-trainer model. *International Psychogeriatrics*, 29,4, 605–614.

Thompson, R. (2017) Life story work for people with dementia with dementia in acute general hospitals. In ' Life Story work with people with dementia – Ordinary Lives, Extraordinary People. Kaiser P. & Eley R. (eds) – Jessica Kingsley Publishers. Pp153-164.

Turner, A., Eccles, F.J., Elvish, R., Simpson, J., Keady, J. (2015). The experience of caring for patients with dementia within a general hospital setting: a meta-synthesis of the qualitative literature. *Aging and Mental Health*, 21(1), 66–76.